

ASSEMBLY, No. 3478

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED FEBRUARY 25, 2020

Sponsored by:

Assemblywoman VALERIE VAINIERI HUTTLE

District 37 (Bergen)

SYNOPSIS

Establishes bill of rights for authorized family members of persons with developmental disabilities.

CURRENT VERSION OF TEXT

As introduced.



1 AN ACT concerning the rights of authorized family members of
2 persons with developmental disabilities and supplementing Title
3 30 of the Revised Statutes.

4
5 **BE IT ENACTED** *by the Senate and General Assembly of the State*
6 *of New Jersey:*

7
8 1. The Legislature finds and declares that:

9 a. Authorized family members of persons with developmental
10 disabilities, including intellectual disabilities, dedicate their lives to
11 persons with developmental disabilities who are their relatives, and
12 authorized family members are an integral part of the framework
13 that supports the health, quality of life, and general well-being of
14 persons with developmental disabilities;

15 b. These authorized family members sometimes face enormous
16 barriers to accessing the supports they need and often feel
17 overwhelmed and worn down by the very system designed to help
18 them;

19 c. While authorized family members have legal rights under
20 federal and State laws, they still face obstacles in asserting their
21 rights and obtaining the appropriate educational, social,
22 recreational, residential, and employment opportunities for persons
23 with developmental disabilities in the least restrictive environment;

24 d. Authorized family members are also the primary advocates
25 for persons with developmental disabilities when accessing the
26 health care system, and they often manage extremely complex
27 diagnoses and treatments within this ever-changing and
28 tremendously complicated system;

29 e. Authorized family members of persons with developmental
30 disabilities also are generally the primary providers of services and
31 supports for their loved ones, often at extraordinary financial,
32 physical, and emotional costs;

33 f. Even when a person with a developmental disability is
34 receiving services from the adult service system, an authorized
35 family member often serves as the de facto case manager,
36 coordinating care, managing services, and ensuring quality and
37 continuity of care of the person with a developmental disability; and

38 g. It is in the public interest to establish a bill of rights for
39 authorized family members of persons with developmental
40 disabilities in order to increase sensitivity about the role of these
41 family members among the State agencies, health care
42 professionals, service providers, and other agencies that authorized
43 family members rely on to support their loved ones.

44
45 2. a. For the purposes of this act, an "authorized family
46 member" is a parent who is a guardian of a person with a
47 developmental disability, or a relative of a person with a

1 developmental disability who is authorized by the person's
2 guardian, or by the person if the person is his own guardian, to
3 receive information concerning the person with a developmental
4 disability. The authorized family member of a person with a
5 developmental disability shall have the right:

6 (1) to be treated with consideration and respect;

7 (2) to receive information necessary on a need-to-know basis to
8 make informed decisions, when appropriate, about the care of the
9 person;

10 (3) to receive information and correspondence in writing;

11 (4) to receive return phone calls within a reasonable time frame;

12 (5) to be given clear, up-to-date, understandable, and honest
13 information about the system of services for persons with
14 developmental disabilities;

15 (6) to be given clear information about the authorized family
16 member's status within the service system and what the family
17 member can reasonably expect from the service system currently
18 and in the future;

19 (7) to have meaningful participation and input into, and ongoing
20 review of and involvement with, the person's plan of care,
21 including, but not limited to, an individual family service plan,
22 essential lifestyle plan, and individualized habilitation plan;

23 (8) to have a method of recourse if the authorized family
24 member feels the person's plan of care is not being implemented or
25 the person is not receiving adequate care appropriate to the person's
26 needs;

27 (9) to be free from retaliation if a complaint is made; and

28 (10) to be advised in writing of any laws, rules, or regulations
29 regarding the ability to access information or participate in
30 decisions about the person's life, including, but not limited to,
31 guardianship issues and access to records, reports, plans of care,
32 and other pertinent information.

33 b. The rights set forth in subsection a. of this section shall be
34 designated as the "Bill of Rights for Authorized Family Members of
35 Persons with Developmental Disabilities," and a list of these rights
36 shall be prepared and distributed by the Division of Developmental
37 Disabilities in the Department of Human Services to every case
38 manager of a person with a developmental disability. The list shall
39 be posted in a conspicuous place in each office of the Divisions of
40 Developmental Disabilities and Disability Services in the
41 Department of Human Services, in each State developmental center
42 listed in R.S. 30:1-7, and in each group home operated or overseen
43 by the Division of Developmental Disabilities.

44
45 3. This act shall take effect on the first day of the third month
46 next following the date of enactment.

STATEMENT

This bill establishes the "Bill of Rights for Authorized Family Members of Persons with Developmental Disabilities." The bill defines "authorized family member" as a parent who is a guardian of a person with a developmental disability or a relative of a person with a developmental disability who is authorized by the person's guardian, or by the person if the person is his own guardian, to receive information concerning the person with a developmental disability.

Under the bill, an authorized family member of a person with a developmental disability has the following rights: to be treated with consideration and respect; to receive information necessary on a need-to-know basis to make informed decisions, when appropriate, about the care of the person; to receive information and correspondence in writing; to receive return phone calls within a reasonable time frame; to be given clear, up-to-date, understandable, and honest information about the system of services for persons with developmental disabilities; to be given clear information about the authorized family member's status within the service system and what can reasonably be expected currently and in the future; to have meaningful participation and input into, and ongoing review and involvement with, the person's plan of care; to have a method of recourse if the authorized family member feels the person's plan of care is not being implemented or the person is not receiving adequate care appropriate to the person's needs; to be free from retaliation if a complaint is made; and to be advised in writing of any laws, rules, or regulations regarding the ability to access information or participate in decisions about the person's life, including, but not limited to, guardianship issues and access to records, reports, plans of care, and other pertinent information.

The "Bill of Rights for Authorized Family Members of Persons with Developmental Disabilities" is to be distributed to every case manager of a person with a developmental disability. It is also to be posted in a conspicuous place in each office of the Divisions of Developmental Disabilities and Disability Services in the Department of Human Services, in each State developmental center, and in each group home operated or overseen by the Division of Developmental Disabilities.